Monitoring symptoms at home: What methods would cancer patients be comfortable using?

Kleiboer, A.M.; Gowing, K.; Holm Hansen, C.; Hibberd, C.; Hodges, L.; Walker, J.; Thekkumpurath, P.; O'Connor, M.; Murray, G.; Sharpe, M.

published in
Quality of Life Research
2011

DOI (link to publisher)
10.1007/s11136-010-9662-0

document version
Publisher's PDF, also known as Version of record

Qual Life Res (2010) 19:965–968
DOI 10.1007/s11136-010-9662-0

BRIEF COMMUNICATION

Monitoring symptoms at home: what methods would cancer patients be comfortable using?

Annet Kleiboer · Katie Gowing · Christian Holm Hansen · Carina Hibberd · Laura Hodges · Jane Walker · Parvez Thekkumpurath · Mark O'Connor · Gordon Murray · Michael Sharpe

Accepted: 13 April 2010 / Published online: 6 May 2010

Abstract
Purpose This study aimed to determine which methods of remote symptom assessment cancer outpatients would be comfortable using, including those involving information technology, and whether this varied with age and gender.
Methods A questionnaire survey of 477 outpatients attending the Edinburgh Cancer Centre in Edinburgh, UK.
Results Most patients reported that they would not feel comfortable using methods involving technology such as a secure website, email, mobile phone text message, or a computer voice on the telephone but that they would be more comfortable using more traditional methods such as a paper questionnaire, speaking to a nurse on the telephone, or giving information in person.
Conclusions The uptake of new, potentially cost-effective technology-based methods of monitoring patients' symptoms at home might be limited by patients' initial discomfort with the idea of using them. It will be important to develop methods of addressing this potential barrier (such as detailed explanation and supervised practice) if these methods are to be successfully implemented.

A. Kleiboer (✉) · K. Gowing · C. Holm Hansen · C. Hibberd · L. Hodges · J. Walker · P. Thekkumpurath · M. O'Connor · G. Murray · M. Sharpe
Psychological Medicine Research, School of Molecular and Clinical Medicine, University of Edinburgh, Kennedy Tower, Royal Edinburgh Hospital, Edinburgh EH10 5HF, UK
e-mail: annet.kleiboer@ed.ac.uk

Keywords Symptom assessment · Oncology · Cancer outpatients · Modes of assessment

Introduction

The assessment and management of symptoms is an important part of the care of cancer patients. As cancer treatments are increasingly delivered in outpatient and primary care settings, we need to develop efficient and acceptable ways of monitoring patients' symptoms when they are at home and not just when they visit the hospital.

Methods that could be used for home monitoring of symptoms range from traditional domiciliary visits to those using new technologies, such as secure websites, mobile phone text message, and computer-generated telephone calls [1]. These new methods are potentially more cost-effective [2, 3], less time-consuming [4], more reliable and faster in providing data [4], and some studies have found that patients are more honest about their symptoms when using them [5, 6].

However, patients may not always feel comfortable using these novel methods. This may be because they are not familiar with them [7, 8] because they miss the human interaction with a doctor or nurse [9, 10], or because they are concerned about their privacy and the security of the data [9, 11]. How comfortable patients initially feel about using these new methods is likely to affect their willingness to use them, and consequently to create a potential barrier to the implementation of these innovations into routine practice [10].

We report on a service development audit that aimed to determine which methods of symptom assessment outpatients of a Cancer Centre said would be comfortable using, and whether these views varied with patients' age and gender.

Materials and methods

Design

A cross-sectional questionnaire survey.

Sample

The study sample consisted of 477 consecutive cancer outpatients aged 18 or over who were attending selected clinics of the Edinburgh Cancer Centre for follow-up visits between March and May 2006. The clinics selected were for patients with breast, prostate, gynaecological, sarcoma, colorectal, haematological, and lung cancers. These clinics were chosen to obtain a patient sample that was representative of gender, age, and common cancer types. All attending patients were eligible for inclusion. Patients who were too ill, had cognitive impairment or had severe communication difficulties were excluded.

Ethical approval

We were advised by the local Research Ethics Committee that, as this was a service development audit, ethical approval and written patient consent were not required.

Measures

Patients were asked to rate how comfortable they would be 'to give information about your symptoms' using the following symptom assessment methods: face-to-face, telephone (nurse you have met), paper questionnaire, telephone (nurse you have not met), email, secure website, telephone (computer voice), mobile telephone text message. Responses were made on a four-point scale ('not at all', 'a little', 'a lot', 'completely'). Information was also collected from patients regarding their age, sex, computer and internet access at home, and whether they owned a mobile telephone.

Procedure

Consecutive patients attending the selected clinics for follow-up appointments were eligible to participate. After checking in at the clinic reception, patients were approached by one of the researchers and invited to complete the paper questionnaire while they waited for their consultation.

Analysis

Anonymised aggregate data were analysed. First, patients' views about the different methods of symptom assessment were described. Second, the association between these views and patients' age and gender was determined using logistic regression. For these analyses, patients' responses were dichotomised so that 0 = 'not at all' or 'a little' and 1 = 'a lot' or 'completely' to make the findings easier to interpret. Age was categorised into three age groups: ≤45, 46–60, >60. A multivariable model was used for each endpoint (i.e., face-to-face, telephone (nurse you have met), paper questionnaire, telephone (nurse you have not met), email, secure website, telephone (computer voice), mobile telephone text message).

Results

Sample

During the study period, 585 patients attended the selected clinics and 477 (82%) agreed to participate; 39 patients were not approached due to busy clinics; and 69 declined. The study sample was predominantly women (323/477, 68%). Participants had a mean age of 62 (range 19–91 years, SD = 12.5 years). Approximately half the sample (273/477, 57%) had a computer at home and (235/477, 49%) had internet access. Most patients (348/477, 73%) owned a mobile telephone.

Views on methods for symptom assessment

Patients' views on how comfortable they would feel using different methods of symptom assessment are shown in Fig. 1. The majority indicated that they would feel comfortable giving information face-to-face, on the telephone to a nurse they had previously met or on paper. Most patients also indicated that they would be comfortable giving information on the telephone to a nurse they had not previously met, but they were more divided with respect to this method. Substantially fewer patients reported feeling comfortable using methods involving technology such as mobile phone text message, a telephone computer voice, a secure website or email.

As shown in Table 1, patients' views about methods of symptom assessment were associated with gender and age. Men were more likely to report that they would be comfortable giving information about symptoms using a secure website, email or by text message. Younger patients were more likely to indicate that they would be comfortable using a paper questionnaire, a secure website, e-mail, or text message.

Discussion

Most cancer outpatients reported that they would feel comfortable giving information about their symptoms

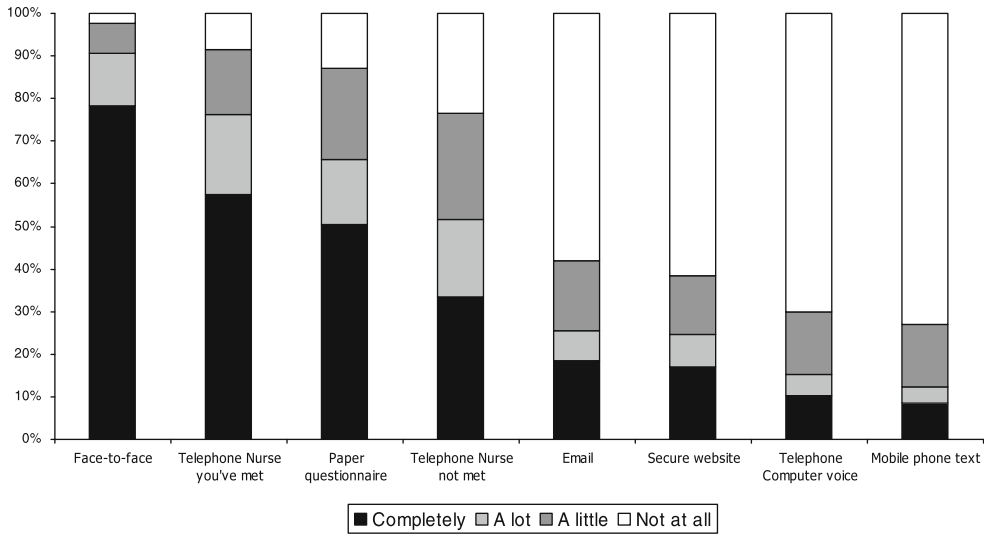

Fig. 1 Patients' views on how comfortable they would feel using different methods of symptom assessment

Table 1 Percentage of patients who felt 'a lot' or 'completely' comfortable with different methods of symptom assessment by gender and age

	Total ($n = 475$) n (%)	Gender		*P*	Age in years			*P*
		Male ($n = 154$) n (%)	Female ($n = 321$) n (%)		≤ 45 ($n = 55$) n (%)	46–60 ($n = 152$) n (%)	> 60 ($n = 268$) n (%)	
Face-to-face	430 (91)	144 (94)	286 (89)	.20	45 (82)	139 (91)	246 (92)	.12
Telephone: nurse you have met	363 (76)	115 (75)	248 (77)	.50	39 (71)	120 (79)	204 (76)	.46
Paper questionnaire[a]	310 (65)	107 (69)	203 (63)	.08	41 (75)	106 (70)	163 (61)	.02
Telephone: nurse you have not met	247 (52)	90 (58)	157 (49)	.07	25 (45)	79 (52)	143 (53)	.73
Email[b]	109 (23)	45 (29)	64 (20)	<.001	24 (44)	49 (32)	36 (13)	<.001
Secure website	116 (24)	51 (33)	65 (20)	<.001	25 (45)	48 (32)	43 (16)	<.001
Telephone: computer voice	73 (15)	29 (19)	44 (14)	.18	8 (15)	21 (14)	44 (16)	.87
Mobile phone text message	59 (12)	25 (16)	34 (11)	.02	13 (24)	21 (14)	25 (9)	.004

P-values are from multivariable logistic regression analyses of the effects of age and gender. Data on age and gender were available for 475 patients

[a] Total $n = 474$, female $n = 320$, 46–60 $n = 151$

[b] Total $n = 473$, male $n = 153$, female $n = 320$, 46–60 $n = 151$, >60 $n = 267$

face-to-face, on the telephone to a nurse they had met before, on a paper questionnaire, or on the telephone to a nurse they had not met before, although patients were more divided with respect to their views on the last method. Substantially fewer patients reported feeling comfortable using methods involving information technology, such as email, a secure website, a telephone computer voice, or mobile telephone text message. Whilst methods using technology (a secure website, email or mobile phone text message) were found more acceptable by younger patients and by men, it was still only a minority of these patients who reported feeling comfortable with these methods.

There have been few previous studies of the initial attitudes of patients to remote symptom monitoring methods using technology. Those of which we are aware have also found limited enthusiasm for these methods [7, 12, 13]. However, studies that have examined the acceptability of these new methods *after* the patients have used them have reported greater acceptability [14–16]. Furthermore, there is some evidence that initial reluctance may be overcome by providing patients with the experience of actually using the technology [8, 17]. The main challenge in implementing such methods therefore may be to find ways of overcoming patients' initial reluctance sufficiently for them to gain familiarity with them.

As experience seems critical to overcome the initial reluctance to use these new methods, it may be useful to have a mock-up of the equipment available in the clinic for patients to tryout under supervision. Patients may also be more willing to use new methods if the benefits of the method are made clear, if they are provided with a careful explanation of how it works, and if its privacy and security are assured [1]. Additionally, enthusiasm for these methods depends on the burden imposed on patients which can be minimised by using brief questions, or computer adaptive testing–based methods, especially when assessments are frequent. Studying the effect on uptake of different ways of increasing patients comfort with these technologies will be important in telling us the best way to achieve effective implementation.

These findings must be considered in the context of several methodological limitations: First, whilst we aimed to obtain a representative sample of cancer outpatients, our findings may not be generalisable to all cancer clinics. Second, in this study, we did not explore in detail why patients did not feel comfortable using some methods but were with others. Finally, the data for this study was collected in 2006 and the access to and the use of technology has increased somewhat since then.

Implications

Enthusiasm for potentially cost-effective technology-based methods of monitoring patients' symptoms at home should be tempered by these findings of limited initial acceptability. Methods to improve their acceptability and uptake, such explanation and practice, will be required before routine implementation is considered. And if given the choice, some patients may still prefer more traditional methods of assessment.

References

1. Rose, M., & Bezjak, A. (2009). Logistics of collecting patient-reported outcomes (PROs) in clinical practice: An overview and practical examples. *Quality of Life Research, 18*, 125–136. doi:10.1007/s11136-008-9436-0.
2. Davalos, M. E., French, M. T., Burdick, A. E., & Simmons, S. C. (2010). Economic evaluation of telemedicine: Review of the literature and research guidelines for benefit-cost analysis. *Telemedicine Journal and E-Health, 15*, 933–948. doi:10.1089=tmj.2009.0067.
3. Friedman, R. (1998). Automated telephone conversations to assess health behavior and deliver behavioral interventions. *Journal of Medical Systems, 22*, 95–102.
4. Pare, G., Mirou, J., & Sicotte, C. (2007). Systematic review of home telemonitoring for chronic diseases: The evidence base. *Journal of the American Medical Informatics Association, 14*, 269–277. doi:10.1197/jamia.172270.
5. Newman, M. (2004). Technology and psychotherapy: An introduction. *Journal of Clinical Psychology, 60*, 141–145. doi:10.1002/jclp.10240.
6. Richman, W. L., Kiesler, S., Weisband, S., & Drasgow, F. (1999). A meta-analytic study of social desirability distortion in computer-administered questionnaires, traditional questionnaires, and interviews. *Journal of Applied Psychology, 84*, 754–775.
7. Pinnock, H., Slack, R., Pagliari, C., Price, D., & Sheikh, A. (2006). Professional and patient attitudes to using mobile phone technology to monitor asthma: Questionnaire survey. *Primary Care Respiratory Journal, 15*, 237–245. doi:10.1016/j.pcrj.2006.03.001.
8. Carlson, L. E., Speca, M., Hagen, N., & Taenzer, P. (2001). Computerized quality-of-life screening in a cancer pain clinic. *Journal of Palliative Care, 17*, 46–52.
9. Bielli, E., Carminati, F., La Capra, S., Lina, M., Brunelli, C., & Tamburini, M. (2004). Wireless Health Outcomes Monitoring System (WHOMS): Development and field testing with cancer patients using mobile phones. *BMC Medical Informatics and Decision Making, 4*, 7.
10. Werner, P., & Karnieli, E. (2003). A model of the willingness to use telemedicine for routine and specialized care. *Journal of Telemedicine and Telecare, 9*, 264–272. doi:10.1258/135763303769211274.
11. Ahmad, F., Hogg-Johnson, S., & Skinner, H. (2008). Assessing patient attitudes to computerized screening in primary care: Psychometric properties of the computerized lifestyle assessment scale. *JMIR, 10*, e11. doi:10.2196/jmir.955.
12. Eikelboom, R., & Atlas, M. (2005). Attitude to telemedicine, and willingness to use it, in audiology patients. *Journal of Telemedicine and Telecare, 11*(S2), 22–25.
13. Brick, J., Bashshur, R., Brick, J., & D'Alessandri, R. (1997). Public knowledge, perception, and expressed choice of telemedicine in rural West Virginia. *Telemedicine Journal, 3*, 159–171.
14. Kearney, N., McCann, L., Norrie, J., Taylor, L., Gray, P., McGee-Lennon, M., et al. (2009). Evaluation of a mobile phone-based, advanced symptom management system (ASyMS) in the management of chemotherapy-related toxicity. *Supportive Care in Cancer, 17*, 437–444. doi:10.1007/s00520-008-0515-0.
15. Bush, N., Donaldson, G., Moinpour, C., Haberman, M., Milliken, D., Markle, V., et al. (2005). Development, feasibility and compliance of a web-based system for very frequent QOL and symptom home self-assessment after hematopoietic stem cell transplantation. *Quality of Life Research, 14*, 77–93.
16. Wolpin, S., Berry, D., Austin-Seymour, M., Bush, N., Fann, J. R., Halpenny, B., et al. (2008). Acceptability of an electronic self-report assessment program for patients with cancer. *CIN-Computers, Informatics, Nursing, 26*, 332–338.
17. Demiris, G., Speedie, S., & Finkelstein, S. (2001). Change of patients' perceptions of telehomecare. *Telemedicine Journal and e-Health, 7*, 241–248.